

.....
(Original Signature of Member)

118TH CONGRESS
1ST SESSION

H. RES. _____

Expressing support for the designation of “Batten Disease Awareness Day”
on June 9.

IN THE HOUSE OF REPRESENTATIVES

Mr. BEAN of Florida submitted the following resolution; which was referred
to the Committee on _____

RESOLUTION

Expressing support for the designation of “Batten Disease
Awareness Day” on June 9.

Whereas Batten disease is a fatal rare disease of the nervous
system that usually begins in childhood, and is the most
common form of a group of disorders called neuronal ce-
roid lipofuscinoses, or NCLs for short;

Whereas there are approximately 13 known mutations of
Batten disease, typically referred to as CLN1 through
CLN14, which are all variants of lysosomal storage dis-
orders;

Whereas Batten disease is an inherited genetic (autosomal re-
cessive) disorder whereby brain cells are missing an en-

zyme which creates a buildup of metabolic waste, and as a result, the cells gradually lose their function;

Whereas Batten disease is known as a rare disease, and its prevalence occurs in approximately 2 to 4 out of every 100,000 births in the United States each year;

Whereas symptoms of the disorder vary significantly, and they often include patients exhibiting developmental delays, experiencing seizures, vision loss leading to blindness, and loss of motor skills and the ability to walk, talk, or communicate, and some children also endure cognitive decline, personality and behavioral changes, dementia, and other severely debilitating physical ailments;

Whereas depending upon the age of onset of symptoms initially presenting, it can take from a few months to several years for a child to obtain an accurate diagnosis of Batten disease, and unfortunately, misdiagnosis frequently occurs on the family's journey through the diagnostic odyssey;

Whereas Batten disease currently has very few treatment options available, and it results in premature death occurring between early childhood and early adulthood;

Whereas there presently is no known cure for any form of Batten disease; and

Whereas we recognize June 9 as “Batten Disease Awareness Day”: Now, therefore, be it

- 1 *Resolved*, That the House of Representatives supports
- 2 the designation of a “Batten Disease Awareness Day”.